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ABSTRACT

This booklet is a collection of stories by people who have facilitated Personal Futures Planning groups. The groups provide an individualized, structured approach to life planning for people with developmental or other disabilities and have been implemented since 1988 in Minnesota. Introductory material describes the process, which starts when a focus person, people who care about the focus person, and a group facilitator come together to develop a Personal Profile of the focal person's history, relationships, strengths, and other aspects of that person's life. In ensuing meetings the group develops a vision of a desirable future for that person, the members make commitments to actions that could help realize that future, and members share ongoing successes and failures. The stories, all from the point of view of the facilitator, include case studies, anecdotes, and vignettes. They stress successful use of the method to solve problems, empower individuals and their families, and celebrate community life. (DB)

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"LISTEN, LADY, THIS IS MY LIFE"

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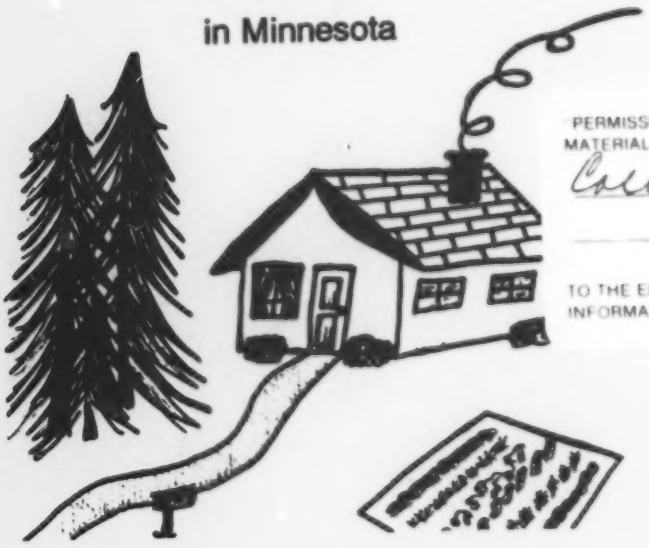
A Book of Stories About Personal Futures Planning in Minnesota



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1990-91 Personal Futures Planning Project

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"LISTEN, LADY, THIS IS MY LIFE"

A Book of Stories

About

Personal Futures Planning

in Minnesota

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Artwork by Patricia J. Lyon and Jeph Lyon

ABOUT PERSONAL FUTURES PLANNING

Personal Futures Planning is an individualized, structured, possibility-based approach to life planning. A Personal Futures Plan represents a vision for a more desirable future. The plan is developed by a group of people who care about the individual and are willing to assist in making the plan a reality. Then, the group continues to meet to bring about changes in the person's life toward the better personal future.

Personal Futures Planning can be used for anyone, at any age -- it's a PEOPLE process based on bringing people together. In many states, including Minnesota, Personal Futures Planning has primarily been used with and for persons with developmental disabilities.

The process starts when a focus person, a group of people who care about the focus person, and a group facilitator come together. The participants often need to be willing to discover what they don't know about the focal person and about what's possible for that person's life. The first meeting consists of a Personal Profile, which looks at a person's history, relationships, strengths, gifts, and other aspects. Many people, even those who have known the focus individual for a long time, report being able to see the person in brand-new ways as a function of the Personal Profile. In the second meeting, the group develops a dream or vision for a desirable future for the person. People make commitments to certain actions to help bring the dream into reality. Then, the group continues to come together to share successes and failures and to continue to move toward the dream. Often the process is an experience of giving power, know-how and support back to individuals with disabilities and their families.

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PERSONAL FUTURES PLANNING

IN MINNESOTA

Since 1988, the Minnesota Governor's Planning Council on Developmental Disabilities has sponsored three consecutive years of training in Personal Futures Planning. Approximately 350 people attended one-day introductory sessions. More than a hundred individuals all over the state have been trained to facilitate Personal Futures Planning groups. In the first year (1988-89), the Metropolitan Council on Developmental Disabilities sponsored this training, primarily in the Twin Cities area. In the second and third years (1989-91), the Human Services Research and Developmental Center sponsored the training throughout Greater Minnesota.

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This work is more art than science. The solution is as likely to come from your imagination as from your rational mind. It is not a matter of designing programs but of creating visions; not of following protocols but fulfilling dreams. And believing in those dreams: believing that a woman who has been isolated could still have friends, or that a man whose life has been controlled could still escape and be free. Trusting that kind of vision means learning to hope.

The Gift of Hospitality, *Mary O'Connell*

ABOUT THIS BOOK

Judith Snow urges us to dream more than plan. Plans tend to become hardened -- they lose the capacity to change. If you take the first step toward a dream, the dream will change as you go along. The dream will be changed by reality, but the dream will also change reality.

One Candle Power, Pat Beeman, George Ducharme, and Beth Mount

This is a book of stories about change. Some are about changes in the lives of people with disabilities who are moving toward the fulfillment of their dreams through the process of Personal Futures Planning. Others are about the people and agencies that support people with disabilities that have been changed by learning about and utilizing the Personal Futures Planning process.

A great deal has been learned in Minnesota over the past three years as more people have been introduced to and begun to use Personal Futures Planning. Perhaps the greatest lesson learned regards the nature of change itself. We keep learning that change is a process -- a journey, not a destination. Perhaps committed, caring people just coming together to work on dreams is in itself one of the most important changes. Sometimes, even the simplest and smallest of changes for an individual is still a huge accomplishment. On the journey toward dreams we sometimes encounter obstacles, detours, and actual roadblocks. In spite of the challenges, the Personal Futures Planning journey has brought many rewards in the lives of the people involved in the process.

It is the intention of this book to celebrate community life and successes, and the use of Personal Futures Planning to help people find and have their visions.

This book is a collection of stories by some of the persons who have facilitated Personal Futures Planning groups. Some of these groups have lasted a short time and some a long time. Some of the groups have been able to make a difference in small ways, and some have enabled gigantic changes to happen for the person with disabilities. Some of the stories are lengthy and some are "moments in time." They all reflect the on-going process of learning to see in new ways.

The stories are written from the perspective of the group facilitator.

* * * * *

The people who contributed the stories in this book are:

Angela Amado	Human Services Research and Development Center
Wendy Annis	Cooperating Community Programs
Wendy Bartz	Adaptive Living Programs
Terri Bauernfeind	Partnership Resources
Dennis Burgess	Faribault Regional Center
Catherine Conzet	Mary T., Inc.
Joyce Eckes	Hennepin Technical College
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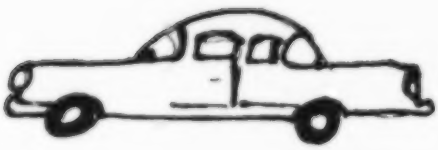
Jan Manchester	St. Paul Public Schools
Jenny Mateer	Washington Co. Social Services
Marijo McBride	Institute on Community Integration--University of Minnesota
Wendy Nelson	Willmar Public Schools
Mary Pieper	Houston County Group Homes
Dave Ross	Harry Meyering Center
Ruth Soderstrom	Friendship
Hans Swemle	Dakota, Inc.
Kay Zwernik	Metropolitan Council



"LISTEN, LADY, THIS IS MY LIFE"

Craig, like many children, had a somewhat ambivalent relationship with his mother. Although they clearly loved each other, they also often had a hard time with each other. Sometimes his mother teased him, and sometimes he blew up at her. And, as is often the case with children in their 20's, sometimes it's hard to know how much to "mother" and how much to "let go."

Now in his late twenties, and having been shifted around to a lot of different living situations, Craig was hopefully "settling down" in an apartment with a roommate. Although Craig said many things, it was sometimes difficult to understand exactly what he was saying because he often did not speak very clearly. He also sometimes seemed to not quite understand what was going on, especially if things were taking a long time. You could never be quite sure how much he understood.

On the particular night we met, Craig was doing just fine with the Personal Futures plan. He seemed to understand exactly everything that was being said, and even said a few things himself. His mother was participating in the Futures Planning meetings to provide as much information as possible about Craig's history and background.

Craig was sitting in a new armchair which he had just bought that weekend. As the Personal Futures charts progressed, his mother started teasing him and bugging him about different things. Was this his shirt? Yes, it was his shirt. Was it his chair? Yes, it was his chair. Then he started saying more about what he wanted on the charts about his dreams for his future. As his mother started bugging him again, he turned to her and said very loudly and very clearly, "Listen, lady, this is MY life."

No line expresses more the essence of Personal Futures Planning -- honoring people's lives as THEIRS. We thank Craig for the title of this collection of Minnesota stories about Personal Futures Planning.

JIM AND JOE

I received a call to do a Personal Futures Plan from a man named Joe. Joe had gone to college in Minnesota in the early 1970's. In 1974 his fraternity had invited persons who lived in a regional treatment center (state institution) to visit their fraternity and experience typical college life and friendship. Joe had become friends during that period with one of these visitors, Jim, who was recommended to move out into a community group home. After moving on and then living in another state, in 1990, Joe began wondering what had happened to Jim after all this time, and how he was doing. Since Joe lived in another state, he had to make many phone calls and finally found out that Jim was still living in the same regional treatment center.

Joe initiated a Personal Futures Planning process for his friend with some wonderful outcomes. The group helped to reunite Jim with his family. His sisters and brothers had not had contact for years, and had images of Jim being "a vegetable," not able to walk or talk. They were astounded to find out how capable Jim is with his hands, and how independent he is. Jim had his first visit home in a number of years, and that was to celebrate Christmas.

After sixteen years Jim and Joe's friendship has picked up again and flourished. The two friends have shared remembrances of activities they enjoy, phone calls, and cards. Joe has visited Minnesota several times and shared time with Jim doing things of interest. The two friends, Jim's family and the circle of support have made many dreams and plans for Jim moving into a new home, having a new job, and having a fuller life being included in society. Several different homes have been considered, and plans are actively underway for Jim to move.

EMILY AND MICHAEL

This is a story about two five-year-olds, their parents, and their schools. It is a story about what their parents and school staff learned from the Personal Futures Planning process. Both of the five-year-olds transitioned from special education early childhood programs into regular kindergarten programs in their neighborhood "home" schools. Their neighborhood schools had never before had children with this degree and range of disabilities in regular kindergarten.

About Emily and Michael

Michael uses gestures, sign language, pictures, and some words and phrases to communicate. He has been classified as moderately mentally handicapped, and has motor planning problems and sensory challenges.

Emily was born premature, and has cerebral palsy along with significant sensory and processing challenges.

Personal Futures Planning was chosen as a process for these two children because they were at a crossroads. The parents needed to make decisions about their children's transition from early childhood to kindergarten. After we talked to the families, we decided together that Futures Planning could help them define their dreams, look at the available options, and help them with their decision-making process. Also, for young children, educational programming is probably one of the most important factors in the child's life. But staff and families wanted to look beyond just school programs, and look at the whole person and the whole community. We wanted to look at Emily and Michael not just as kindergarteners or as students, but as the whole person each of them is. Personal Futures Planning was a process that would also help us with that.

Prior to the Futures Planning process, the parents of Emily and Michael had really enjoyed their partnership relationship with the school staff. Because of their advocacy and involvement with their children, it was felt that Futures Planning was a fitting process.

The families were involved in all the preparations for the Futures Planning. The early childhood staff sent home materials about Futures Planning, talked with the parents and answered their questions, and involved them in the basic formatting of the process. We pulled different elements from the entire process to tailor it to the needs of the children and their families.

For the Futures Planning meetings, staff of the early childhood program and the parents invited the people who would be the possible players in these children's future kindergarten programs. Both the kindergarten teachers and the principals of the schools the children would attend were invited to come. The Futures Planning meetings were attended by the parents, and staff from both the receiving and sending schools. Emily's principal came, and a representative from Michael's Child Study Team staff attended. The kindergarten special education teacher who would be responsible for their afternoon programs also came and ended up acting as a special liaison, building bridges, and advocating for Emily and Michael with the regular kindergarten teachers.

We had just one large Futures Planning meeting, with many mini-meetings after that with two-three people involved in the mini-meetings.

<u>From Emily's mom:</u>

At the Futures Planning meeting, Emily's mother said, **"We had hopes for her. But we never told people those hopes because we didn't think they could happen."** In the Futures Planning process, these parents were encouraged to dream and were supported in taking the steps they needed to take to make it

happen. Emily's parents believe the information and ideas shared in the Futures Planning process helped them realize their dreams of Emily going to her neighborhood school. The Futures Planning process helped the staff at her neighborhood school see her as a whole person, not just as a 'child with disabilities.' Futures Planning is really a story about Emily's life and her dreams. It was so helpful because it was like reading a story about Emily. Her story was a personal, strengths-based story for the child study team at her receiving school.

Emily's mother said that the Futures Planning process was helpful to them in moving them on to the bigger world. In the early childhood program, they were comfortable, and felt taken care of and supported. With the Futures Planning Process they had the "loudest voice" and their advocacy for Emily was reviewed and affirmed by Emily's network of support.

Emily's mom and dad wrote a letter to the principal of the receiving school introducing Emily and sent along her futures plan. In their letter, they highlighted what they needed and wanted to happen in transitioning Emily from early childhood to kindergarten. The principal became a real advocate for Emily. Although he was retiring, he passed on the information to the new principal, who has become very involved in Emily's program. The new principal was able to act on these issues right away. She set up the needed materials and support to happen during the school day, so that Emily did not need to be pulled away to a special section of her school for her special eating and toileting needs.

The principal also involved Emily's parents in the hiring and selection of the paraprofessional in the kindergarten room. Although this paraprofessional was hired with Emily in mind, she supports the kindergarten teacher with all the children, has the information pertinent to Emily regarding what works for her, helps her learn and helps her participate. Emily's parents were empowered that their voice was heard, that their thoughts and ideas were part of the staff selection process. Emily's mother sees this new principal as being invested. Emily's parents and the principal are beginning to explore together the options for the next school year.

Emily's mother said, "Although it was initially time-consuming, the benefits continue to be reaped from the futures planning process." One of the biggest advantages is having the futures plan on paper. "I have this paper. I can pull this out and say, 'See, this is what we decided.' It's a support to us as we advocate for Emily."

From Michael's mom:

Michael's mother had been unsure of what educational program or program combinations would be best for Michael. Michael's mother reported that the process affirmed their dreams, and afforded them the courage to pursue their dreams.

It was extremely valuable to the kindergarten teacher, in reading Michael's futures plan and going over it with his family, to find out what the family wanted for Michael during his time in kindergarten. The kindergarten teacher understood that Michael's parents wanted him to have a variety of literacy opportunities, like writing, journaling, drawing. Most important to them, however, was that Michael would develop friendships and have fun. The teacher knew then what the parents valued and where to focus her energy. Michael's mother was excited that Michael made marks and drew pictures on paper, and then he wanted other people to write a story about the marks he had made. It was not important that he could not recite or print the ABC's.

Staff and Programs

Both families wanted their children to attend kindergarten sessions in the morning, as that's when they would be most fresh and alert. This scheduling also happened as a result of the Futures process. Secondly, they wanted their children to have physical and occupational therapy in the afternoon, at their special kindergarten program in another school building. This schedule allows them to receive that therapy.

When both children started school in the fall, the Early Childhood staff was part of the transition plan. They came to the new school and supported the children and staff, then gradually weaned away. There had been lots of phone calls, networking and connecting as part of the "Steps of Action" process in the Futures Planning. As a result, this web of support and collaboration was set up beforehand to support Emily, Michael, their families and teachers in this life transition. This web allowed familiar staff persons to support the children, and knowledgeable persons to support the new staff.

Both Michael and Emily had been in Early Childhood programs for children with special needs. Their morning program had had opportunities for inclusion, with preschoolers from regular preschool programs coming three mornings a week for shared learning and play experiences. However, the typical progression for both Michael and Emily to kindergarten could have been to attend school enrolled in a classroom for children with special needs in a specially designated regular education building. They would have had inclusion opportunities, but the program they would have attended would not have been their neighborhood school. Before the Futures Planning process, neither set of parents had articulated that this was their dream: for their child to go to their neighborhood school.

Their neighborhood schools had previously provided regular kindergarten to some children who received special education services. However, this is the first time children with more significant disabilities have been fully included in regular kindergarten. Once the vision was shared with Michael and Emily's school district administrators, they were catalysts in helping to make it all become a reality.

The Child Study team at the receiving school told the early childhood teacher from the sending program that they had never before had children with this degree of disability, and they were hesitant. The Futures Planning process diffused their discomfort, and really helped the staff overall in being prepared for Michael and Emily's coming. What they had known about Michael was that he used sign language,

pictures, and some words and phrases to communicate. But, reading the Futures Plan Personal Profile, they could really find out: Who is Michael? As a result of the Profile, they saw him as a human being, as a child who was fun and friendly. The staff felt really excited about the information they shared as a result of the Futures Planning process, and that it was very helpful in making the transition happen. By being planful and collaborative, their fear was very much reduced.

One of the most helpful things to the staff from the Personal Profile information was the list of "Things that Work" and "Things that Don't Work." The school said, "You don't receive that type of information on an IEP when you get a new child. You usually just receive the educational goals. You don't receive information on strategies that really help the children in learning, participating, and connecting."

The Futures Planning process affected the staff at the receiving school and how comfortable they were. Because some of them had been participants in the planning process for each of the children, they were invested in supporting them.

As a result of the process, many support staff also received information that allowed the transition to be very smooth. For instance, the speech and language specialist understood that she would be supporting Michael in his classroom, not pulling him out for speech and language therapy.

One of the most important things the staff and families learned is that things that looked like "barriers" aren't always immovable. We have learned that we can share our dreams, and that there are people out there who will support us in our dreams.

Busses

Michael's mother thought the Futures Planning was very worthwhile and the time spent made a big difference -- in particular, Michael is now riding the regular school bus to school. She had been so scared about that. But in the "Steps of Action" part of the process, that issue was explored together.

She didn't have to look at it alone, she could look at different options and do her looking with staff.

Michael's 4th grade sister Laura rides the same bus. When Laura was sick for four days, Michael went by himself. His mom said to me, "Can you believe I didn't even think about him getting on the bus all my himself?" Something that had been so great a fear had been talked over, and then it happened. "I didn't even think: what will Michael do without Laura?" Michael doesn't always use speech to communicate, but the other neighborhood kids and the bus driver know him now, and she didn't even think about his riding alone being a problem.

One of the big questions, that had seemed to get in the way for the school staff, was: how could Emily ride the regular school bus? She has a walker and a wheelchair, and the school busses were not equipped for this kind of equipment. Her parents pursued the question, and kept finding out answers to questions affecting other kids -- like, if a kid had a tuba he brought to school, where would he put it on the bus? Working with the school district with the Futures Plan as their guide, Emily's parents removed another obstacle.

Both Families

Both families have copies of the Futures Plan to share with their relatives, friends, and neighbors. They feel that the Futures Plan is a way to share with others: "Who is my child and what are my dreams for my child?"

Both parents felt supported from the Futures Planning process and doing the "Steps of Action." They felt supported that they did not need to make decisions alone or before they were ready to. They could follow the steps: to learn more about the school program, to check out options. They didn't need to make decisions right away and they didn't need to make them alone.

Both families intend to revisit this planning process in the future, when they have other decisions to make. They want to use it to explore again: what do we value for our child? and,

what are our options? They see themselves as pioneers and trail-blazers for their children. The school district has supported looking at many different options. They have said: home school is an option, what kind of support and services do you need to stay at your home school? And, what are the other options? What is best for Emily? What is best for Michael?

Emily and Michael are doing great.

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About 47 family and friends came to our first planning meeting. The focus person volunteered to make the coffee throughout the day. This became very significant because she had been living in a locked unit at a regional treatment center. Some of the people at the meeting who had not seen her in a long time thought she was helpless or dangerous. At this meeting in the public library, socializing with everyone and making coffee, she managed to ease everyone's anxieties.

She has moved out of the regional treatment center and is living in a home in the town in which she grew up. She has many opportunities to visit with family and friends.

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CHUCK

Chuck is in his 30's and lives in an apartment with two other guys. He has a job boxing in a warehouse, with support.

Chuck invited the following people to be in his Futures Planning group: his staff Marjorie, Val, and Steve, a friend of his named Jane, and members of a family that were friends of his (two parents and two adult children in their 20's). His meetings have been continuing for about two years, with most of this group continuing as members.

Partly as a result of the futures planning meetings, Val and Steve have also become friends with Chuck, more than just "staff," and do many things with him.

As a result of expressing and being supported in having some of his dreams, several things have happened for Chuck. He's turned into "Mr. Vacationer," and has taken trips to Duluth, Memphis and other places. He loves woodworking, and had a woodshop in his garage but now also has gotten a workshop set up in the basement of his home. He's a swimming fanatic, and goes swimming with Val. He goes lots of places with his friends, including movies and out to eat. He's also taken cooking classes.

Chuck had a dream of being independent in the community. Staff and his case manager and others thought that he could never really be independent, because of his seizures. But now Chuck is getting to have that, too. Staff have moved to "shadowing" (following) him when he goes into the community, and will eventually fade out even that, as Chuck becomes even more "on his own." He is working on being his own guardian. Chuck also calls together his group for his own Futures Planning meetings, when he wants to or feels the need to have one.

FRIENDS

Dean's planning group is primarily composed of members of his family, and now and again staff people join in the Personal Futures Planning process. At the onset, we concentrated on the problems we perceived Dean was having with his living and working situations. For the first few meetings, the group did little problem-solving or creating new visions for the future, but some members spent a good deal of time blaming Dean for the problems that existed in his life.

When we started Dean's Personal Futures Planning process, he lived in a house with two other men with disabilities. He wasn't very happy there. Eventually, he moved to a home where he had only one roommate with disabilities and things seemed to improve both there and on his job, as well.

As time passed, the group changed also. The real turning point for the group came the day we were talking about relationships and Dean told us that he sometimes got lonely and that he just wanted to have a good friend. Then it hit us: most of us were lonely too. What Dean wanted was really no different than what each of us wants for ourselves. We were all more alike than we were different. Why should we think that Dean would feel any different? We saw that the real problem was not Dean but rather the absence of friends in his life.

We started to treat each other as friends. Our get-togethers were no longer meetings but celebrations. From then on, we validated Dean's feelings as "normal" and like our own. We now talk with one another as friends. His family seems to be developing a new relationship of friendship as well as kinship with Dean. He now holds a more valued and valuable position in his family. We've been able to move on to helping Dean develop relationships both inside and outside of his planning group. We all are continuing to learn about the give and take nature of relationships, and the importance of friendship in all our lives.

JOHN'S STORY

John is twenty-five years old and has Down's Syndrome. He has lived in a 15-bed group home, a "Class A Intermediate Care Facility for the Mentally Retarded" (ICF-MR) since May of 1984.

John is a very personable young man, and has had two dreams for a long time. He wanted to live in his own apartment, and he wanted to work somewhere other than the sheltered workshop -- preferably at the Hardee's restaurant in a neighboring town. The small town in which he lives does not have a Hardee's or any other fast food restaurant.

Staff and John's "interdisciplinary team" had been listening to John say for at least the past two years that he didn't want to live at the group home or work at the sheltered workshop. Many of John's friends had had the opportunity to move into apartment settings in the past several years and John was feeling that he, too, would enjoy that opportunity. However, there are always risks involved in moving someone from the safety of the group home into a real home in the community and there are always the questions of readiness and funding and . . . and . . . and . . .

Annual and semi-annual reviews of John's progress showed significant improvement in all his "goal" areas. Work reports from the sheltered workshop indicated that he was not happy there and his productivity was not anything to brag about. The Personal Futures Planning process gave John the opportunity to formally tell the people in his life who cared, or who had some influence, just what he wanted and how badly he wanted it.

Members of John's Futures Planning group included his mother, who was his legal guardian, a representative from the sheltered workshop, the job recruitment person from the local Developmental Achievement Center, his case manager, and from the group home: his staff advocate, program supervisor,

program director, and the director of the Semi-Independent Living Services/Waiver programs. This planning group met twice in its entirety. Numerous meetings of smaller groups were held in between the big group meetings.

In response to John's dream to live in his own place, John's case manager was agreeable to having him go through the formal screening process for funding under the Medicaid Waiver. This screening was completed after the first meeting. John easily met the criteria for waiver program funding. However, the county had only a certain number of positions or "slots" under the waiver, and no more were available.

It was at this point that John's mother and the group home staff became aggressive advocates for a creative solution to this "system's" problem. Several issues were happening with a few individuals around the same time: one young man had a family emergency and was facing placement in a state institution (Regional Treatment Center), one person needed a different roommate, a woman needed a smaller home with more intense support, another woman needed "emergency respite" when her parents became ill, plus the agency that operated John's group home was building a small, 6-bed home in a nearby town. There were lots of different problems (like, three of the six people in the new home had to be persons coming from the state institution), but these problems also seemed like they might be opportunities. One thing that happened was some creative placement swapping, including closing an "RTC bed" for one person and opening a "waiver bed" for another. Through all of the proposals and changes, the county case manager remained one of John's strongest advocates. She convinced the state Regional Services Specialist to support the switches as best for all the individuals involved. Both she and the Regional Services Specialist came to bat for John, and managed to get an additional "waiver slot" for John.

John moved into his own apartment on September 23rd, 1991. He has a bedroom, living room and kitchen on the third floor of a huge old home in his hometown. He cooks his own breakfast and makes his own lunch. He shares the downstairs of this house with two other young men, eating his evening

meals with them and participating in recreational and other activities with them. There is always one staff person to support these three young men, and a staff person who sleeps overnight.

John has had his struggles in his new home -- having to cope with new roommates, what appears like more loneliness, fewer staff, and considerably more freedom. However, when asked if he is happy, John is adamant in his reply of "Yes" -- in spite of also being "homesick" for his group home "family."

That's the great part of John's story, that he's living in his own apartment. Working on a different job placement for him has led to more stone walls, but also some positive consequences.

When it came to advocating for a different job placement for John, his case manager appeared to back down -- but the rest of us didn't! During the course of the first large group Futures Planning meeting, it came to light that the Developmental Achievement Center (DAC) had secured a janitorial job in a nearby high school. John was asked if he would like the job and indicated that he would. The DAC pursued the idea and felt that they would be more than able to supply the job coaching that John would need. This job would mean shifting the work responsibility for John from the sheltered workshop to the DAC.

Staff at the sheltered workshop were adamant that this was not a good placement for John, since he had not indicated a desire to do janitorial work in the past and it was not in his program goals to pursue a janitorial job. John's mother pushed the group home to continue to pursue the high school job, with job coaching from the DAC. John continued to say that he wanted to try this job. It became quite a battle, with the workshop and county case manager appearing to be siding against the group home and John's mother.

The director of the county Human Services Department soon became involved, trying to appease the sheltered workshop and the DAC and encouraging the group home to back off. The executive director of the group home agency told us we had to regroup and realize that "we were at the top of the ninth inning

facing a new pitcher." He did not back down, but continued to encourage the staff to advocate for John, keeping in mind the consequences to the other residents, future programs, and John's proposed community residential placement.

Then the group home staff asked the DAC, sheltered workshop, case managers, and county director of Human Services to get together and put the real issues on the table. This meeting was one that was literally about ten years overdue. It expressed a person-centered approach for everyone -- not just people with disabilities, but also agency directors and county human services staff. We were committed that everyone be in communication about what their real concerns were.

Everyone there found out that the issue was not John, but the way the money flowed. If John were to leave the sheltered workshop and become employed by the DAC at the janitorial job, his job coach would have to be funded as part of the same waivered services rate that was funding his residential placement. The county had been mandated by the state to reduce the total cost of its waivered services programs and they just could not and/or would not put the additional monies into John's job coach, even though it was felt that the amount of job coaching would be systematically reduced.

At this meeting, the funding sources for the sheltered workshop, DAC, and waivered services were finally explained to all the parties. None of us really knew the details of just how the others operated. The impact of those funding sources on placements helped us to at least see where the case manager was coming from, and why she had appeared to be blocking John's work placement. It also helped explain a lot of other "mysteries" in the vocational and work lives of our group home residents. This meeting did not immediately help John, but it sure helped bridge some huge communication gaps.

As a result of all this "boat-rocking" for John, an Interagency Team has been formed with the intent of it to understand how the various agencies providing services to people with developmental disabilities in our county can work together to

provide quality programs. A "SWOT" planning strategy has been undertaken to identify the: Strengths, Weaknesses, Opportunities, and Threats that exist to services in our county. As a result of these sessions, plans have been made to sponsor a legislative forum for parents, to help inform them of what's going on politically. A Speaker's Bureau is in the making that will be available to give presentations to county civic and social organizations about available services within the county. Respite care services are being explored and expanded. And this is just the beginning.

John is still at the Sheltered Workshop. We're still advocating for a job for him in the community, hopefully in a restaurant. We're being a little more patient. We'll let John become more settled and successful in apartment living. And, we'll not forget his dream.

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Often, we have no idea what to do, what will help, but we will struggle together to explore options and share the difficulties.

One Candle Power, Pat Beeman, George Ducharme, and Beth Mount

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"Empower people and families to jointly create solutions and opportunities."

-- David Wetherow

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JAMIE

Jamie is twenty years old and has Down's Syndrome. He lives in his parents' home in the town of Benson and attends Willmar Senior High school. In an attempt to help him feel more a part of his own community, a job site was set up during his school day at a grocery store in Benson in February 1991. Getting this job established involved cooperative efforts between the Willmar and Benson schools, the grocery store manager, county case manager, job coach, and parents.

Shortly after Jamie began his job, we held a Futures Planning session. It was a very supportive group made up of Jamie, four community members; job coach, parent, teacher's aide, and case manager. The positive aspects of this session included the acceptance of Jamie in the community, the desire to work with his strengths, and consensus regarding the most effective approaches in working with him. There was clearly a concern for a high quality of life for Jamie, including focusing on his interests and social opportunities in his community. The job coach was encouraged by the group to continue his successful work with Jamie. The overall approach of Personal Futures Planning allowed us to open our minds to what Jamie is all about, and how we as caregivers can best support him.

RANDY

Randy's school district became interested in Personal Futures Planning after one of their special education staff heard me give a talk about it to their school staff, some parents, and community agencies. The district decided to pursue it, and selected Randy and his family for participation.

Randy has Down's Syndrome. At the age of three he started receiving early intervention services; the benefits of that intervention, a public school education, and family members that love him can be seen immediately. Randy is very outgoing and sociable. His language and comprehension are quite amazing. He understands everything and responds appropriately, without any adjustment having to be made for his disability. His sense of humor is fantastic. One of his dreams is to be a stand-up comic. Randy is liked by the regular education students and students with disabilities. His Special Olympics coach has taken a special interest in him, and Randy has won many medals over the years.

Randy is close to graduation and his parents were becoming anxious about what would happen after school. In his district, the students classified as "TMR" (trainable mentally retarded) are integrated into most classes, and this is true for Randy. He has also been working at Hardee's doing a variety of jobs for two years. His boss attended the first Planning meeting and obviously thinks a lot of Randy.

Randy's and his family's dreams are that Randy will move to St. Cloud, live in an apartment with three other men ("three" is the choice Randy expressed), have a competitive job, date girls, be near a swimming pool, be a country western singer and stand-up comic, ride the bus and be active in the community. He will graduate at the end of the school year in 1992, and his parents will be moving to St. Cloud at that time, also. Part of the plan was for the parents to become Randy's legal guardians.

The school and Randy's family were very pleased with the Futures Planning process and the results. Randy has been trying new recreational ventures. He is now out of the fast food business and is working in a fairly big grocery store stocking shelves and doing odd jobs. His teacher says he is doing very well. We arranged a "community connector" for him and the two meet with each other every so often. The community connector has put Randy in contact with several people and organizations where he can associate with regular young people, including a religious group for young men and a Boy Scout troop for older youth.

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One facilitator was very disturbed because the person's mother was not saying anything at all during the Planning meeting. This was a mother that had often been hostile and angry before, and the facilitator was concerned that she wasn't saying anything because she was so upset.

They talked afterward, and the mother assured him that anger was not the reason she hadn't said anything. Rather, she had been incredibly moved when people in the group shared about their dreams and visions for her son. She said, "I was so emotional I couldn't talk. I never thought people had those dreams for Steven."

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"I want to be free" -- Stephanie

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MARY

Mary has lived in institutions most of her life. She has been in them since age four, and is now in her late thirties. She most recently resided at Cambridge Regional Treatment Center. Her brother, who is her guardian, heard about Personal Futures Planning and contacted me about doing a plan for his sister.

Mary has profound mental retardation, behavior difficulties, a stiff gait, and language that consists of grunts and pointing. She didn't walk until she was almost an adolescent. She is on a lot of medications and is beginning to show signs of dyskinesia. She needs someone with her for orientation at all times and needs physical assistance with all daily living skills.

Mary is one of six siblings and both her parents are living and visit her once a month. Her brother John wanted her to leave the regional treatment center and was having no luck making things happen. Her first Futures Planning meeting was attended by both parents, John, the county case manager, and four or five staff from Cambridge.

The first meeting, the Personal Profile, showed Mary to be a woman who had very few experiences in life, no friends, a significant history of behavioral disabilities, and no understandable language. She has endured years of isolation because of her behavioral difficulties and lots of psychotropic drugs. The Futures Planning process also allowed Mary's gifts to shine through -- she has a family who loves her, a happy

smile, a desire to please and be helpful, an interest in children, a love of the outdoors, showers, sweets, quiet time, and paper shredding.

The vision for the future which the group developed included a small living setting with no more than four people with disabilities in the St. Cloud area, a part time job in the community, a private bedroom to meet her need for quiet time, recreational activities in the community, more family contact, and friends. In the interim, before Mary could move out of the RTC, the family agreed to see her more often and to include her in family get-togethers. The RTC staff agreed to plan community outings for Mary, both for recreation and to check out job possibilities. They also agreed to match Mary with a volunteer.

During the nine to twelve months it took to move Mary out, she had a volunteer college student who visited her and did things with her several times a week for about six months. Mary was included in a family reunion and a celebration of her own birthday in a party room at an apartment complex. She also was visited and taken out not just by John, but also by her other siblings and their families. Mary visited parks, the Dairy Queen, the post office, and several stores in Cambridge including a grocery store. Although staff were initially reluctant regarding these visits, all but one of the excursions were successful, and the staff were very surprised.

In December 1990, Mary moved to her own home, a foster home in the St. Cloud area. Her new home is much closer to her parents and they will be able to see her often and be more a part of her life.

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THE EMANCIPATION OF CHARLES

Clearly, reaching forty years old is a landmark for anyone; it was an especially memorable landmark for Charles. The birthday celebration included many family and friends. Not only did he have a job pressing sheets with steam machinery in a major hotel chain, but he had also been selected "Star Employee" by the company. He was considered a "success story" by the agency staff who worked with him.

A few months after this celebration we began the process of Personal Futures Planning. The Planning group included his family and staff from his group home. After just two meetings it became clear that Charles had a lot of different dreams and different visions of success than we did. Many of these visions could be summarized as the concept of "Emancipation."

"I think I want to work with animals," stated Charles. "But you are so successful at the job the day program found you," replied one of the participants in his Futures Planning group. "You don't understand," said Charles, "machines are cold, they don't offer me anything. Animals are loving and respond to you -- I want that in my job."

Charles had many more ideas for his future. "Different places to live, maybe an apartment, new experiences, maybe a farm, maybe the suburbs -- just everything a new experience."

While we listened to these ideas and saw that many of the ideas Charles had could become a reality for him, the group also worked together and with Charles to identify the different obstacles. Being an adult doesn't just mean being "free" and doing things for yourself, sometimes it also means more work, risk, and sacrifice. Right now, his parents live close to his small group home and provide him with a lot of transportation to many different places. If he moved farther away from them, he could not expect them to keep catering to his transportation and personal needs. While Charles has many social skills, he is very passive at building relationships for himself. If he

wanted to be more independent, he would also have to actively work on developing more relationships and friendships for himself.

The emancipation Charles struggles with sometimes seems similar to that of a teen-ager's power struggles with his parents. The Futures Planning process has allowed Charles opportunities to express his desires for more freedom, and also a safe arena to confront some of the personal responsibility that comes along with that freedom. While sharing his dreams and more readily asserting himself, Charles struggles with the real step of adulthood: taking charge of one's own life.

The group has helped him with this work of personal responsibility for his life. He has business cards printed up with his name and number to help him build relationships with people he meets; the cards say "Call me, call a friend." He has gotten a telephone with large push button numbers to help him communicate with the people he does know and with new friends. His program goals have started to reflect his own expressed wishes -- one of his goals is to, at least once a week, ask someone to have coffee with him.

Charles has gotten a new job doing the laundry for "Horst" hair salons; he excitedly tells people he works with "horses." Given his interest in animals, there is now a pet in his group home and his group helped him get started volunteering at the Humane Society. We are actively working on the new home and new experiences, the dreams he has shared with us.

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When Personal Futures Planning was explained to her, Brenna was initially reluctant to come to the meetings. After the first meeting, she said "I will never forget this day. I didn't know I would have such a chance to talk for myself. I thought this would be just another meeting where they "staffed" me."

Her group thought all the meetings about her should not be called "Staff-ings" but rather "Brenna-ings."

###

MARY O.

I have been Mary's friend and guardian for 14 years. Mary is now 41 and has Down's Syndrome and epilepsy. Her family gave her up at birth and she spent the first 25 years of her life at Faribault and Hastings state hospitals.

For the last 14 years, Mary has lived in a group home with seven other people with disabilities, all of whom have a greater degree of severity in their level of disability than Mary. She is not friends with any of the other seven people who live there. At the time we did the Personal Futures Planning process Mary was working in a "sleaze-bag motel" as a housekeeper. She did a lot of activities in the community, but only in places and at times that involved groups of people with disabilities. At the time of the planning process, she had no other non-paid person involved in her life.

The first part of Mary's Futures Planning process, the Personal profile, revealed that she goes a lot of places in the community, is interested in other people and feels close to several other people with disabilities, loves her job, is independent in self-care, and does a lot of chores around the group home.

Mary is friendly, generally happy but pouts and cries when she is criticized, and is proud of her appearance -- she likes to dress nice and have her hair fixed.

Mary was very clear about her first priority for her vision -- she wants to live in an apartment. She has continued to state this dream for the past several years. My vision for her included her having other non-paid friends and participating in regular community activities in regular community settings.

Some things have changed for Mary in the three and a half years since we started the Futures Planning process. She has started two different jobs since that time. Currently, she does housekeeping at the Super 8 Motel, and is totally independent except for spot checking. Her other job is dusting and window cleaning at Dayton's Home Store. She is extremely proud of her accomplishments at these jobs. She is the only person with a disability at this Dayton's store. Her co-workers really like her and include her in cookie exchanges, coffee breaks, and holiday parties.

Mary now has one other non-paid person in her life. Her job coach Vicki has become very attached to her and takes Mary out to eat, to sleep over at her house, and to a lot of cultural events. Her friend Vicki is very connected to the theater world, so Mary has received free tickets, been able to go backstage and to meet stars. Vicki even took her to get a fashionable "non-retarded" haircut.

These changes are making a big difference in Mary's life. However, trying to change her living situation has been very frustrating. I very recently began efforts to have her live with Vicki, in a situation that would be licensed as a foster home. We hope this will become a reality in the first quarter of 1992.

GORDON

Gordon is a handsome 17-year-old young man with a good sense of humor who really enjoys sports. He has been classified in the moderate-severe range of mental retardation, has had some serious medical problems beginning at an early age, and has some serious behavior problems such as hitting others.

The persons involved in his planning group included his mother, special education teacher, and social worker. His father was either unable or unwilling to attend meetings. Gordon has no siblings, and no interactions with neighbors or friends in his area.

Gordon's mother had been complaining about various things regarding Gordon for a long time. As a result of the Futures Planning process, she started really becoming an advocate instead of just a complainer. She also started to get real support from other members of her family, instead of just sympathy.

The long-range dreams for Gordon and his family included: finding a trustworthy doctor, finding a respite program where the parents could be away from home on vacation for 2-3 weeks at a time, and finding a friend for Gordon for his after-school hours.

Gordon's mother started to take on more responsibility and learned to ask for help when it was needed. Because of the need for respite care, she began a letter-writing campaign to the county commissioners. She wrote, but also got her relatives and people in the Futures Planning group to write letters about the lack of respite funds. Inspired by these efforts, the social worker also started looking into county resources. As a result of both these actions, the county opened up respite funds again. Gordon has been receiving respite care at least one weekend a month now, for over a year.

It used to be rare for Gordon's mother to take him out to events. But since the Futures Planning, his mother has taken him out more into the community. One evening a month, they attend adaptive community recreation sessions in which people play guitars and/or banjos for interested audience members, whether handicapped or not. Information on other community friendship and recreation programs has also been sent to Gordon's mother, and work is continuing on the on-going challenge of finding friend relationships outside of school.

During times that have been stressful with certain doctors and other medical personnel, the school physical therapist has gone with Gordon and his mom to medical and orthopedic appointments to support the mother. Gordon's communication skills have also been re-evaluated to help him experience more success in letting his needs and wants be known.

As Gordon is experiencing more success in his school activities, his mother has become much more positive. She has learned much more about asking for and getting support, and about active advocacy for her son.

###

From a case manager at a Personal Futures Planning meeting:

"From all the reams of social history about (this person), I never really understood why she acted this way until I participated in this. Now I understand her for the very first time. All of the files, reports, and social histories are meaningless when compared with the real picture of her which was developed in this brief meeting."

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DOROTHY AND AGNES

While I was attending a workshop called "Framework for Accomplishment" in September of 1989, I met Dorothy and Agnes. Part of this workshop includes gathering information and asking people about their dreams, and follows the same process as Personal Futures Planning.

Within the first 15 seconds of meeting them, both these ladies told me how much they hated the large residential group home in which they lived -- they hated the food, the noise, the safety, and the people. During the five days of the workshop I came to know them quite well. Dorothy is in her late sixties and Agnes is in her late fifties. Both have been classified as severely mentally retarded and both have epilepsy. Dorothy has a severe hearing loss and uses a walker. Agnes uses a cane or walker for steadiness. They are two lovely older ladies with very natural and normal social skills, despite the years they have both spent living in institutions. Both entered state hospitals as young children and remained until twenty years ago, when they moved to this 125 bed group home. They have been roommates the entire time, are best friends and are very dependent upon each other.

Following the workshop and with the support of their case manager I continued to see them. The case manager and I rewrote their Individual Service Plans to reflect their dreams for themselves. When their dream to live in their own home was not met by the deadline which we specified in their ISP's, the ladies asked me to appeal their case. We did, and had a case management hearing. As a result of this hearing, they were given designated "slots" to move out into their own home. The whole process took about 15 months. They have now lived in their single family dwelling for just over a year.

Their other dreams for themselves are also being realized. They wanted to be more active in their community. They now go to a new Catholic church, to bingo usually twice a week, on regular shopping trips, out to eat, and to a variety of

community events. I keep asking them if they are happy and they continue to tell me they are. They enjoy the quiet, the freedom to do what they want, the opportunity to make things in the kitchen, and for the first time in their lives to live in a real home.

Because they are both so terribly poor, we are also working on getting them part-time jobs so they have more money to spend. These prospects are looking better.

###

I have made three presentations about Personal Futures Planning to parents and professionals with whom I work. I believe that contact with this process and the emphasis it places on person-centered planning versus service-centered planning has enabled professionals to change attitudes.

I have used the Personal Profile information section of Personal Futures Planning in individual program plan (IPP) meetings to assist the team in reviewing an individual's social skills and relationship network. We have also begun to use the "dreaming" or "images of the future" portion as part of the self assessment. It has helped to involve individuals in their own meetings and has aided the team to develop the IPP around the individual's personal preferences.

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"Community networks move as imperfectly as the heart or collective hearts dictate."

-- John McKnight

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CINDY'S WHEELS

I have had the privilege of working with Cindy and participating in the development of her personal futures plan. Cindy is an adult who has cerebral palsy, and a degree of borderline retardation which sometimes means she carries that label also, and sometimes not.

Cindy is a strong advocate for herself and, long before it was popular, she pushed the system (and herself) to move into her own apartment. Ten years ago, she put herself through Courage Center's apartment training program and since then has been living in her own apartment with a personal care attendant. Some time ago, Cindy achieved for herself many of the things that the system is just now seeking for people with handicaps: an independent living situation, full integration in the community, and time to spend with friends and loved ones who care.

At her initial futures planning meeting, Cindy told us that she had tried to get a new motorized wheelchair the year before but her request had been rejected. Her old chair was ten years old, broke down a lot, and was showing definite signs of wear. It seemed reasonable for her to have a new chair. I speculated that Medical Assistance probably rejected her request due to an omission or an error in the application process.

Her planning group discussed other options than a new chair. A friend of Cindy's who also uses a motorized chair talked about the possibility of buying a new motor if Cindy's request

was rejected again. We realized that what was really needed was for someone to be willing to dig through the red tape for her. I felt that that was where I could be useful. Even though I knew nothing about the process, I knew enough to start asking questions.

I soon learned that what Cindy really needed was a medical expert to assess her chair, her positioning, and her needs. After all of the assessments, the expert would formally submit the request for the new wheelchair. In order to begin the process, it was necessary for her own physician to make the necessary referrals. This entire process was very lengthy and took nearly a year to complete.

Members of the planning group supported her in a variety of ways during this time. We talked with her physician and the positioning clinic. We made appointments for Cindy, arranged for her to be there for her appointments, and sometimes even accompanied her. During this time, I talked to companies that manufacture motorized wheelchairs and had their sales representatives attend some of the appointments with Cindy.

It was exciting for Cindy to pick out the features of her new chair: the color and style of the frame, the color and fabric of the upholstery, and the type of foot rests. It wasn't difficult to see the group's enthusiasm as we ventured into this project. It was so contagious that the sales representative for the wheelchair manufacturer got caught up in our enthusiasm and called us the very moment he heard that the application for the new wheelchair was approved. "I am putting the order in today! Just thought you would like to know." We had a mini-celebration upon learning this news -- "mini" because Cindy still had to wait for eight weeks before her new chair would be delivered.

When the chair finally arrived we had a party to celebrate its arrival and to congratulate ourselves for hanging in there. It is a wonderful chair which Cindy says gives "a smooth, quiet and dependable ride!"

HELEN'S STORY

Family is and always has been the central focus of Helen's life. She has an excellent relationship with her mother, who lives in Minneapolis. Her brother lives with their mother, and often takes Helen under his wing, taking her various places. Her sister has also always been a strong ally.

At the time we began dreaming of an "ideal vision" for Helen's future, she was living at a state regional center. She was involved in a supported employment job in the community and loved her work. Helen participated fully in the futures planning process and let those of us in her planning group know what she wanted to accomplish in her life.

Her own vision for the future includes living in her own apartment close to her family. She wants a dog to care for and easy access to transportation. Being close to shopping malls and recreational activities is important. She wants to cook her own meals and have enough money to buy the things she needs. Church is very important to Helen and she hopes to be able to help a pastor with church activities. Her dreams for her future are fairly ordinary and not really expecting too much.

When the staff started working on moving Helen out of the treatment center, they were unable to move her directly into her own apartment. Since her plan was developed, Helen has left the regional treatment center and moved to a group home in southwestern Minnesota. Fifteen people with disabilities live in the home and there are two people in each bedroom. Helen has a job at a motel in town which she likes very much.

The futures planning process gave Helen the chance to say what she wanted. The process gave direction to the placement process, in terms of what is important to Helen. It put her dreams to paper. Some of what she wanted to happen, has happened. Without the process, what Helen wanted would not have been articulated.

Helen's sister also lives in her new home and the two women enjoy each other's company. They have re-established their relationship and are now the best of friends. They frequently picnic and enjoy a variety of activities together. A local taxi provides them access to excursions into the community and shopping at the local mall. Helen visits her mother occasionally, using the bus to get to and from Minneapolis. There are many churches near her home where Helen can get involved. She does not yet have a dog, but hopefully this, too, will become a reality.

Helen seems very happy with her move from the regional center to the group home. This is only the beginning of the movement toward Helen's dream. The planning group has given input to the group home staff on her visions. Helen's mother wants to keep the planning charts up in her house. With the continued support of Helen's planning group, there is good reason to believe that all of her visions will be realized.

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"Small successes keep us going, and sometimes may be the most important thing. We must always remember to celebrate the small wins to give us energy to go forward."

-- Pat Beeman

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SALLY

Sally had been living in an ICF-MR with nine other people who also have developmental disabilities. She hadn't been happy living there -- she wanted to have her own apartment. Sally said she needed more privacy than the group living situation allowed.

Although Sally was her own guardian, her parents had always had a tremendous amount of influence over the choices she made, and they felt that Sally should continue living at the ICF-MR. The other members of her planning group strongly disagreed with Sally's parents and felt that she would do just fine in an apartment. During the Personal Profile section of the Personal Futures Planning meeting, they focused on all of the things that Sally was able to do on her own. By the planning group's second follow-up meeting, her parents finally agreed that, if Sally really wanted to, she could move to an apartment.

The group helped Sally and her parents through the process of having her sister become her conservator. Once that was done, her case manager located an apartment where Sally could have Supported Living waivered services, and she has moved to her own apartment.

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RENEE

Renee is a 6 year old girl who has spina bifida and uses a wheelchair. She lives with her mother, father, and two older sisters in northwestern Minnesota. Renee attends a neighborhood school in a special education classroom. She has many friends both with and without disabilities. Her

family has always been careful to give her many opportunities to participate in a variety of activities.

Renee's mom was not very enthusiastic about a Personal Futures Plan for her. She thought that it probably would not be very effective for a person as young as Renee. For that reason, she did not bring Renee to the planning meetings and had her remain in school. By the end of the first meeting, her mom was in tears after realizing for the first time that Renee had never had a birthday party. The family was always so busy seeing to her needs that they forgot to celebrate her being here! Of course, plans were immediately set in motion to have a big birthday celebration.

Through her mom, Renee communicated her own dreams at the second meeting. She wanted to stop wearing diapers and wear panties like the other girls, and she wanted to learn to walk someday. Tears flowed again as her mom acknowledged that she should have realized that Renee wanted to try to become toilet trained. It had been easier for her to just keep her in diapers. Because of Renee's physical disabilities it is not known if toilet training will be possible to accomplish, but Mom decided that it was time to use training panties regardless of the success or failure of toilet training. Renee is involved in intensive physical and occupational therapy; walking independently, probably with the aid of braces, is one of the goals she is reaching for.

Her mom changed her mind about the usefulness of the Personal Futures Planning process for a child of six. She said that Renee's plan helped the whole family to see her in a new way -- as the delightful little girl she really is.

Renee's mom and her county case manager had worked together at several quarterly and annual meetings, but there had previously been no significant collaborative relationship. As a result of the two days of meetings, they decided that there was a need to carry out some training for other parents in the area regarding various issues, and together they have designed and are carrying out that training.

TONY

Tony is a 21 year old young man with mental retardation and a severe seizure disorder. He lives at home with his parents and two siblings. His developmental delay was noticed at age four, and he has had much medical attention most of his life related to controlling his seizures. He is bright, inquisitive, and handsome, with many varied interests.

Tony is also seen as someone who has a difficult time with changes. He has been at the same school for 15 years, and prefers the same schedule and same structure day after day. In his last year of school, he and his family faced graduation and the question of how he was going to transition to a program for adults. His parents, who have been very supportive his whole life, were very afraid of the future.

His Futures Planning meetings were attended by his parents, teacher and teacher assistant, and county social worker. These meetings centered on what Tony was going to do after school ended: were his parents going to keep him at home? Should he go to a Developmental Achievement Center? If so, which one, and how should the transition be handled? Although Tony did go out from his school program to one community work-site, the group also decided that Tony should be exposed to many more community-based work and recreation sites.

As a result of the meetings, his parents really did face the transition to adult programs. In the last year of school, they toured two-three different programs. After many of these tours, they told Tony's teacher how much they hated them, how they cried after some of the tours, and how difficult it was to face this change.

Also in Tony's last year of school, he did visit and experience many more community-based work sites, and did well at them almost all the time.

His parents began to give Tony more options at home with his food, clothes, and activities. As a result of the Futures Planning process, they started to see Tony as more capable than they had thought.

His parents began to ask more questions, and they also learned how to access the social worker for more information. Tony was able to go through a thorough transition program that enabled him to become comfortable with a major change in his life. His parents felt the Futures Planning process was helpful in assisting them make important decisions for their son, and to do things in his best interest that included his input.

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A mother called me up for some assistance because she was so upset with the county and with not being able to get a place for her son to live. I met with her and her son, and the mother complained most of the time. Then I talked to the county case manager, who complained a lot about the mother. In really listening to both sides, I realized that what was missing was a vision for the son's future. Neither side could agree or work toward anything because there was no agreement on what should happen or could happen. There was no DREAM.

I suggested using the Personal Futures Planning process. We got together and developed the dream. What both sides wanted was a home for the young man. The mother had been upset because she kept being told there were "no waiver slots." When it became clear in the group that the dream was for a home, rather than for any particular type of money, we could discuss many different kinds of options. Eventually the young man moved into a foster home.

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At one futures planning meeting, the focus person's mother was tearfully sharing the experiences of seeing her son's life slip out of control. She shared of her frustrations and fears. At one point, her son placed his arms around her and said, "It's all right, Mom." All of the people in the room were captivated by his strength and caring. The effect was an immediate commitment to change his life situation.

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GARY

When he returned home two years ago, Gary's family had been very happy to have him home after many years in an institution. His mother admits to being a little "over-protective" of both Gary and his younger sister, who also has severe mental retardation.

During the Personal Futures Planning session it became apparent that Gary's mom was having a very difficult time trying to meet the needs of both of her children who were living at home. Gary's case manager felt that he should be living in an ICF-MR, but his mother wouldn't hear of it. The planning group suggested that perhaps moving to a foster home would be an appropriate compromise.

With the help of several members of the planning group, Gary's case manager was able to find a couple, the Jordons, who were willing to be Gary's foster parents. They live near Gary's family and attend the same church as his family. While they are interested in providing a real home for Gary, they realize that it is not necessary for them to be his family since he already has a concerned, loving family nearby. Once the necessary paperwork was completed, Gary moved in with the Jordons and seems to be adjusting quite well. His parents visit Gary in his new home approximately once a week and have him home for visits once a month. His mother can hardly believe that she is able to feel good about Gary living away from home.

MICKEY

At times the Personal Futures Planning process can affect not only an individual with disabilities but also their family, and every member benefits from the planning.

As part of the Personal Futures Planning Facilitator Training, Mickey was chosen as a focus person. Mickey lived with her mother and sister and attended a day training and habilitation facility working half days at a commercial laundry. She was chosen by the staff at the facility as a likely person to benefit from Futures Planning. Mickey did not have much opportunity to access the community. It was felt that the planning might help integrate and connect her with activities and community members.

The first meeting went fairly well. It was facilitated by two trainees and attended by Mickey's mother, county case manager, and four people representing the day training and habilitation facility. The Personal Futures Plan included a planned two-week vacation to northern Minnesota, a two year plan to move to northern Minnesota to be with family and friends, and several strategies for Mickey to access her neighborhood more frequently. However, the second meeting, held the following day, proved to be fairly challenging.

During the first meeting people had been very talkative and many good ideas and insights had been suggested. The second meeting started off with no enthusiasm and much underlying tension. After an hour the group took a break. During the break the facilitators were informed that on the previous day, after the first planning meeting, the county case manager found out that Mickey's sister had moved to northern Minnesota and that Mickey was left home alone from 10:30 in the evening until 7:30 in the morning.

Mickey was diagnosed with severe mental retardation, has physical limitations due to childhood encephalitis, has a visual impairment, and is grossly overweight. She also has poor

mobility, uses a walker, and would be unable to get up if she fell. Furthermore, Mickey was unable to use a telephone and Mom had no emergency contingencies in place. Thus, the county case manager had felt obligated to file a Vulnerable Adults Report. The county case manager felt that although Mickey was her own guardian, she was unable to give informed consent and was extremely vulnerable during her time alone.

What had been a fairly productive initial planning session took a turn to how best to "service" Mickey between the hours of 10:30 p.m. and 7:30 a.m. What followed was a list of residential, respite, and personal care attendant options, and who should contact them. Mom in the meantime was asked to find somebody to stay with Mickey during the hours in question.

The group decided to convene in four to six weeks, after having completed their homework in securing "services." Between the second and third meetings, it was learned that Mickey could not access respite or personal care attendant services and that a residential placement would not occur soon.

During that time, Mickey and her mother did take a vacation to northern Minnesota as planned. Mickey and Mom had a very nice vacation and returned with the news that Mom was considering purchasing a small family-run corner grocery near her hometown.

One of the positive aspects of the previous meetings had been Mom's desire to move to northern Minnesota to be near friends and relatives. Their vacation reduced the two year plan to "as soon as possible."

The third meeting was held with Mickey, her mother, one facilitator, and staff from the day training facility. The county case manager was unable to attend but had informed the facilitator that it was important to attempt to plan for night time emergencies.

Two things emerged from this third meeting: a means for neighbors to check on Mickey at night, and also a plan for Mickey and her mother to relocate to northern Minnesota.

After that meeting, things happened very quickly. Mickey's mother decided to not wait to purchase the store, she received several job offers in her hometown, and within three months of the first Personal Futures Planning meeting, Mickey had moved to northern Minnesota. She is living in her old hometown, near other family and friends of the family.

It might be that in trying to "service" Mickey, Mom was pushed to move. However, had the Personal Futures Planning not identified the desire to move closer to friends and family, it is unlikely this would have happened.

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FROM TIM'S MOM:

I used to hate coming to meetings for Tim. Coming to meetings always meant what Tim couldn't do, what he wasn't doing.

In our Futures Planning meeting, his dad was able to see that his dreams for his son were his own dreams. Going to college had been his Dad's dream, not really his dream for his son. Now his dad can have dreams for Tim.

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DONALD

Donald is a 37 year old man with mental retardation who lives in a group home in a small town in northern Minnesota. Because his hometown is so small, Donald has had an opportunity to participate in many community activities and make many friends. He has a reputation for being somewhat of a "ladies man," and is quite popular with the women at the Developmental Achievement Center. Frequent hugs and occasional kisses were often exchanged during work hours. The staff at the DAC have spent a good deal of time explaining appropriate behavior in the job environment to the people who attend the program.

During his planning meeting, Donald told of how he had been regularly attending the same church for the past 12 years and had always wanted to be an usher but had never been asked. His job coach, who also happened to be a member of the congregation, was a participant in the meeting and said he would be happy to inquire about what it would take for Donald to become an usher. Within a few days the arrangements were set and two weeks later, Donald was an usher. Dressed in a new suit, he proudly escorted people to their seats. One of the young women from his DAC came to church and was so surprised and excited to see him in this important role that she ran up to him and exclaimed, "Donald, I want to hug you!" Donald replied in his most dignified voice, "Well, no; not here in church!" Since then, Donald continues to usher one or two Sundays each month.

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By working together we overcome obstacles that we are unable to change by working alone. By giving our gifts, our energy, and our hearts to each other we become empowered to build a future we desire. This is the gift of a circle of support.

One Candle Power, George Ducharme

"A VERY *PERSONAL* PERSONAL FUTURES PLANNING"

I want to tell a very personal story which shows how Personal Futures Planning can be used effectively with many different age groups, types and severities of disabilities, and systems. I would like to share the story of my father's stroke and subsequent Personal Futures Plan. I hope to illustrate how Futures Planning was successfully utilized in supporting a person who is aging to have a dream for the future and do what is necessary to realize that dream.

Two years ago, when he was 75 years old, my father suffered a stroke. Even though it was a minor stroke and not life-threatening, we knew immediately that not only was his life changed inexorably, but so were the lives of all of us who love him so much.

It was during this difficult time that I was reminded of Dorothy Peters'* wisdom when she suggested that Personal Futures Planning ought to be used to plan for the futures of people who are aging. I began to see that my father might be the perfect person and this might be the perfect time to try the Futures Planning process and see if Dorothy's idea was right.

I talked with my father and other members of the family to see how everyone felt about doing a Personal Futures Plan. Everyone agreed that this might be a way to resolve some of the problems confronting us all as a result of Dad's stroke, and so the process of creating some new visions for his future began.

*Dorothy Peters is a long-time member of the Minnesota Governor's Planning Council on Developmental Disabilities. She sat on the Council's Grant Review Committee and after learning about Personal Futures Planning recognized its value as a tool for planning not only for people with developmental disabilities but for many individuals, including people who are aging.

Right off the bat, we ran into two common challenges that occur when doing futures planning: locating a facilitator and arranging for the planning meetings. We were working within very tight time constraints. My sister and her husband were coming from Colorado for a long holiday weekend. They would only be here for a few days, so we scheduled the meetings during their visit. In the interest of time, I decided to be the facilitator for my father's plan.

The whole family gathered, so we had a wonderful turnout. There were my father and mother, my two sisters and one brother, their spouses and children all participating. We began with a common activity of our family -- an informal dinner.

Remaining true to the Personal Futures Planning process, we utilized the same tools and asked the same questions that would have been used if the plan were being developed for a person with developmental disabilities. We used the process to discover my father's gifts and capacities and created not only a vision for a better future for him but we also developed a plan for the rest of the family.

One of the first things that we realized while doing the history is that each of us remembered things in a different way. We felt that this was a good thing which allowed us to see a more full, multi-dimensional picture of our parents. We also discovered that some of us didn't want to admit that anything had really happened. Our family was fortunate that one of my sisters is a rehabilitation specialist who was able to translate the medical reports for us, and my other sister is a speech pathologist who was able to contribute to our awareness of our father's disabilities and his prognosis.

We also made a surprising discovery during the meeting: although we consider ourselves a close family, no one person had the telephone numbers of everyone who would need to be notified in the event of another family medical emergency. We organized the telephone numbers and also made a record of our parent's medical identification numbers.

Dad was very specific about his vision for the future and had many ideas about how his family, friends, neighbors and the system could support him with dignity and without taking away his independence. Included in his vision for the future were the desire to have quality time with his family, to continue to live in his own home, and to have as much independence as possible in all aspects of his life with as much support as necessary in order to achieve his dreams.

When the initial planning meeting was over we had identified goals which would begin movement toward the vision and members of the planning group committed to perform tasks which would support the vision in a variety of ways. We left with a renewed sense of the value of life and a shared vision of a better future for my father.

Since the initial meeting, the vision has not changed. However, some new methods for supporting the vision have evolved. For example, some time after the Personal Futures Planning meetings, Mom mentioned that she was having trouble sleeping because she was afraid that something might happen to Dad during the night. We solved the problem by having grandchildren take turns spending the night. This was a solution which worked well for everyone.

Personal Futures Planning continues to be a process with many ups and a few downs. I am proud to have learned the skills of facilitating this process which gives us permission to dream while learning to problem-solve. We have learned it is okay to be upset with the system and even with each other; but, most of all, we have learned how my father's vision for his future and our support of that vision allow him to enjoy his life to its fullest.

OTHER CHANGES IN THE LIVES OF PEOPLE WITH DISABILITIES WHO HAVE PERSONAL FUTURES PLANNING GROUPS

(reported in facilitators' reports 1990-1991):

New homes

New jobs

Family members -- parents, brothers and sisters, cousins -- are visiting more

Parents are participating more in the person's life and are more interested

There is more cooperation among the different agencies in R.'s life

The focus of school has changed from "day care" to more vocational and recreational focus

Staff attitudes have changed about B.

An interpreter has been assigned to M. for the first time in 13 years of school, and all the people who interact with him are using a uniform language system in communicating with him

The furniture in V.'s room was rearranged more to her liking

The parents of T., who is nine, had built a wheelchair accessible playhouse for him. He used the planning group to tell everyone exactly what he wanted in the playhouse.

N. is more involved in high school activities, goes to more sports events, and has more teen-age friends.

L. is taking the bus from Austin, Minnesota, to visit his family in the Twin Cities on his own.

The person is:

- taking swimming lessons

- getting a driver's license

- moved from a foster family home to a more independent apartment

- going out on dates, now that her staff have set up a chaperoned dating system

- abusing himself far less

- learning the driver's manual

- getting a subscription to a gardening magazine

- moved to his first own apartment from his family's home

- moved from a group enclave at sub-minimum wage to individual supported work at minimum wage

- joining a church group

- has a community job he likes

For other people, planning group members are working on supporting the person in:

- researching vacation options, helping M. raise money to take vacations

- being her own guardian

- joining a Star Trek fan club

- getting a new wheelchair

- "A whole new life for this lady"

SYSTEMS CHANGE STRATEGIES

From the experiences shared with us by persons trained in and implementing Personal Futures Planning in the last four years in Minnesota, and from these stories, we have compiled "systems change strategies." In examining the stories and listening to the people, these are what the facilitators and planning groups did to actually bring about changes for the person. These lists represent the concrete actions which persons undertook to make change happen. Some of these changes were at the individual level, some at the level of the agency or organization, and some at the county and state level.

The next two pages contain two lists. The first is the list of the strategies that made a difference in setting up and/or implementing the Personal Futures Planning group. The second is the list of the strategies utilized after the initial planning sessions were over, and what people did to actually make the plan become a reality.

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STRATEGIES FOR THE PLANNING PROCESS ITSELF

1. Personal commitment: Take the initiative yourself to sort out "red tape"
2. Involve community members
3. Listen to the problems -- determine how they can be solved
4. Deep personal commitment to change by a (non-staff) personal friend
5. PFP process that involved high-level policymakers
6. Using process at important transition points--preschool to kindergarten, high school to work
7. Making specific plans for the future to empower staff becoming responsible for the child
8. Giving parents the safe space and opportunity to express their real dreams
9. Involving persons in power (e.g., school principal) in the process
10. Using the process to get support for more "risky ventures"
11. Letting the person call together his own group
12. Really listening and honoring people's dreams for themselves
13. Really listening to what people express as their wants
14. Using the process to allow family members to gain their "voice" as advocates
15. Using the process to generate a dream shared, and to evaluate different ways to have the dream fulfilled

ONCE THE PLAN IS DONE, HOW TO HAVE IT BECOME REALITY

1. Listen to a person, see how much like yourself they are.
2. Involve community members
3. Reconnecting person with long-out-of-touch family members
4. Thoroughly sharing the information from the process with others involved in person's life, and thereby getting cooperation and support
5. Having smaller sub-meetings
6. Getting policymakers (e.g., county case manager, state staff) committed to person's dream so they'll advocate for him
7. Getting all the county agencies in communication and understanding each other's situation
8. Getting family involved more in person's life
9. Arranging for "community connector"
10. Working in cooperative efforts with all other agencies necessary, toward a shared dream
11. Working with case manager to have ISP reflect person's dream
12. Holding case management appeal hearing
13. Letter-writing campaigns
14. Allowing interested community members, family and friends to see a person as they really are now, not long-ago images or stories
15. Using parts of the process to help person express his dreams and preferences better in the formal planning process

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FOR FURTHER INFORMATION

Additional information about Personal Futures Planning and about facilitators is available from the Human Services Research and Development Center (612-227-3292). Other publications about Personal Futures Planning by the Minnesota Governor's Planning Council on Developmental Disabilities and other printed resources include the following:

Available from the Minnesota Governor's Planning Council on Developmental Disabilities:

Making Futures Happen: A Manual for Facilitators of Personal Futures Planning. By Beth Mount.

Never Too Early, Never Too Late: A Booklet about Personal Futures Planning. By Beth Mount and Kay Zwernik.

Minnesota Governor's Planning Council
on Developmental Disabilities
300 Centennial Office Building
658 Cedar Street
St. Paul, MN 55155
(612) 296-4018

Available from Communitas, Inc. for a fee:

Person-Centered Development: A Journey in Learning to Listen to People with Disabilities. By Beth Mount, George Ducharme, and Pat Beeman.

Imperfect Change: Embracing the Tensions of Person-Centered Work. By Beth Mount.

Dare to Dream: An Analysis of the Conditions Leading to Personal Change for People with Disabilities. By Beth Mount.

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